



Early intervention service coordinators understand that a young child's disability impacts the entire family.

Understanding family members and learning how to effectively support them will help the service coordinator in her efforts to partner with families.





Grandparenting





If you are a grandparent raising grandchildren, you are not alone:

- 6.3% of children in the United States under age 18 (4.5 million) live in grandparent-headed households (Census 2000)
- There are grandparent-headed households in every socioeconomic and ethnic group



When a child is born with disabilities, parents are not alone in their concerns. Grandparents are often anxious too, not only for their grandchild, but for their child whose life is affected by the baby. “I want to be involved in my grandchild’s life, but I don’t want to interfere. I wish my son (or daughter) would tell me how I can help, “ say many grandparents. “We need and appreciate our parents’ support,” say their children, “but we must also know they respect us and how we’re handling our situation.”



Early Childhood Connections asked parents and grandparents how grandparents can assist families of young children with disabilities. The result is an article for parents to share with grandparents.

This is how grandparents can help families of children with special needs, say families:

1. Offer support, but don't hover

“The most beneficial thing my husband’s family did for us was to offer unconditional love and support, even though they didn’t understand all the aspects of our son’s disability,” said one mother. “They asked to learn more about the disability so they could help,” she added.





“When our child was born, my husband and I just wanted our parents to let us be children again, just for a few moments,” said one mother. “We wanted to sit and cry and have them hold us, and listen to us and comfort us. I felt like: ‘I’m hurt and scared, and I want my mom.’”

Grandparents’ support is important to parents as they make decisions about medication, therapy, education, and other aspects of life with a child with disabilities, said a mother. “To know that my parents have confidence in our ability to raise our child gives me confidence, “ said another mother.

“Grandparents need to be careful not to take over,” said a mother, “Let the parents discover for themselves what needs to be done.”



2. Ask how you can help in practical matters

Open communication is important, said both parents and grandparents. If grandparents don't know how to help their child's family, they should say so. Then they should ask what their children would like them to do.

One set of grandparents used their sewing and carpentry skills to make equipment for their grandchild's therapy. "It was a huge help for us. They provided things that would have cost five times as much through a catalog," said the mother.



Another grandmother, whose grandchild with special needs lives in another area, found resources at her daughter's request. She located a Twin Cities therapist whose specialty was unavailable in her grandchild's community, and she purchased books about the disability that her daughter wanted but could not find.

Baby-sitting helps. Said a grandmother: "When we can, we will. If we have other commitments, we won't. The first time I said 'No,' I was worried that my daughter would be upset, but instead she thanked me for my honesty." The daughter said she felt liberated because she learned her parents baby-sat because they wanted to and not out of sympathy.



Another mother said she appreciated her in-laws arranging their schedules to babysit, because they knew it was difficult to find appropriate care for an infant with a disability.

Some grandparents go to medical and other appointments with their children and grandchild. They bring moral support, plus an extra set of ears or hands. A grandmother said the appointments help her learn more about the disability. A parent said her in-laws' accompanying her to appointments meant her husband could remain at work.



The grandparents fielded questions from relatives about a newborn's disability, said a mother. That did two things: 1) it spared the parents from having to explain the situation, and 2) the relatives got factual information rather than gossip.





3. Learn as much about the disability as possible

When grandparents become informed about a child's disability, it indicates, "I really want to be involved. I want to go through this with you," said a mother.

"My parents were afraid to care for my baby because of her medical needs, and it felt like rejection," said another mother. "If they had learned how to care for her, perhaps they wouldn't have been so fearful."

"Grandparents, be careful of the language you use in speaking about the child's disability," said a mother, "If you don't know the words to use, ask the parents what they prefer."



4. Offer opinions if asked

"Sometimes my parents say things that sound as if they think we aren't doing things right," said a mother. "For example, my child has difficulty eating. My mother has said 'She does just fine when she's with me.' That might have been Mom trying to reassure me, but that's not how I heard it."

It hurts when her parents, who live in another area and are not involved in the day-to-day care of her child, question how she and her husband deal with their child's disability, said another mother.



5. Accept the grandchild as he or she is

Treat the child with a disability as you would any grandchild, said parents and grandparents. Both generations caution against favoring the child with or the siblings without the disability. One parent would like to tell her child's grandparents: "Our child is different. Please acknowledge her difficulties. Don't try gloss over them to make her sound perfectly normal."



One set of grandparents say they grieved when their grandchild was born with a disability, but they tried very hard not to let their children know. "Our attitude was this baby is here, and we're going to love him like any other child," said the grandmother. She looked on the child's disability as a new experience. "It's an experience I didn't expect to have, but I won't look upon this as a negative experience."

Her husband later told a friend whose newborn grandchild has a similar disability, "There are a lot more positives than negatives about this."



Complete activity

10.5a Father's Involvement
according to the instructions in
the *Roadmap for the Journey-A
Trainer's Guide*.

Return to this PowerPoint and
resume slides for more
information on the families in the
above article.